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## Plan Overview

*A Data Management Plan created using DMPonline*

**Title:** Een(zorg)ethische analyse van de COVID-19 beleidskeuzes

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### Project abstract:

The measures that the Dutch government took in the first half of 2020 to curb the COVID-19 pandemic successfully slowed down the rate of contaminations and hospitalisations. However, the social and economic costs were high. From an ethical perspective, it is problematic that the far-reaching governmental decisions during those months often lacked a sound ethical argument, or were only accompanied with one-sided utilitarian justifications. This is also troublesome, since the measures especially impacted groups that already found themselves at the margins of public and political attention before the crisis started. Their voices and experiences were not, or barely, included in processes of decision making. At the same time, in the context of stories about exhausted hospital workers and the devastating impact of lockdown measures on vulnerable groups, there was a growing public awareness that care and being cared for are crucial for human flourishing and sustaining a just society. The importance of care and voice, especially for people in the margins, has long been emphasised by care ethicists like Tronto, Sevenhuysen, and Robinson. Therefore, their work seems to be a helpful lens to look back at, and evaluate, the COVID-19 crisis response in order to learn lessons for the future. This project aims to do exactly that, by analysing the drastic policy decisions of the first months from a care ethical perspective, as well as by mapping their impact on vulnerable groups through empirical research. Combined with the reflections of policy makers, these are the building blocks for a new framework for policy making that is ethically coherent and that contributes to a caring democracy, which is resilient enough to respond to future crises in a more inclusive way. This research project consists of four elements. The first is an analysis of the Dutch governmental COVID-19 policies and how these were translated into protocols and measures in the care sector. The focus will be especially on the underlying ethical assumptions and arguments. The second element is a qualitative study that consists of semi-structured interviews and focus groups with people in a vulnerable position, their relatives, professional care workers, and managers. To cover a wide range of care arrangements, four groups will be included: People receiving palliative care, people with mental illness receiving residential care, the elderly living at home who are dependent on informal care, and refugees who have no stable residency. On the one hand, the aim of the empirical research is to understand how the crisis measures impacted the already vulnerable position, the experienced quality of life, and possibilities for hearing the voices of the different groups. On the other hand, the study seeks to explore what creative solutions people found to cope with the impact of the pandemic and the emergency policies. The third element of this project is the drafting of a policy framework based on a care ethical reflection that combines the findings of the policy analysis and the empirical research. This framework will be developed together with policy makers and discussed during

round tables with Dutch and international (care) ethicists, as well as policy makers from several sectors, especially education and culture. After these consultations, the framework will be finalised. The fourth element is dissemination: the framework will be presented during a conference with relevant national policymakers. Smaller events will be organised with and for the four vulnerable groups that are at the centre of this project. Through online and offline publications of the policy framework, academic papers, and the network resulting from this project, the dissemination of the lessons learned will be ensured.

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# Een(zorg)ethische analyse van de COVID-19 beleidskeuzes

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## Data Summary

### 1. Briefly introduce the types of data the research will create. Why did you decide to use these data types?

De data die worden verzameld zijn voornamelijk kwantitatief van aard, met name gegevens over de verspreiding van COVID-19. Dit omvat gegevens over het aantal besmetten, overlevingspercentages, en de effectiviteit van verschillende interventies. Daarnaast worden ook kwalitatieve gegevens verzameld, zoals interviews met experts en patiënten, om de context van de data te begrijpen. De keuze voor deze data types is gebaseerd op de behoefte aan zowel harde cijfers als aan inzicht in de menselijke aspecten van de pandemie.

## Data Collection

### 2. Give details on the proposed methodologies that will be used to create the data. Advise how the project team selected will be suitable for the data/digital aspects of the work, including details of how the institution's data support teams may need to support the project

1. Data collection: First, we need to determine the type of data to be collected. This may include quantitative data (e.g., age, gender, income, etc.) and qualitative data (e.g., satisfaction, preferences, etc.). Data can be collected in a variety of ways, such as online surveys, face-to-face interviews, telephone interviews, or extracted from existing databases.

2. Data cleansing: After collecting data, we need to perform data cleansing to ensure the quality of the data. This may include removing duplicates, dealing with missing values, correcting incorrect inputs, etc.

3. Data Analysis: We can then analyze the data using various statistical methods and tools. This may include descriptive statistical analysis, inferential statistical analysis, predictive modeling, etc.

4. Data Visualization: Finally, we can use visualization tools such as charts and graphs to present the data. This can help us understand the data better and communicate our findings to others.

Here are some suggestions on how project teams can adapt to the data/numerical aspects of their work:

1. Training: Project teams may need to be trained in data management and analytics. This can help them understand how to handle and analyze data using various tools and techniques.
2. Resources: The project team needs to have adequate resources to collect, clean and analyze data. This may include software, hardware, manpower, etc.
3. Collaboration: The project team needs to work closely with other team members (e.g., the data support team) to ensure the quality and accuracy of the data.

For more information on how the organization's data support team may need to support the project, here are some suggestions:

1. Provide technical support: The data support team can provide technical support to help the project team process and analyze the data.

- 2□Provide data resources: The data support team can provide a variety of data resources, such as datasets and databases, to support the data needs of the project.
- 3□Provide training: The data support team can train the project team in data management and analysis.
- 4□Provide consulting: The data support team can provide professional consulting on data processing and analysis for the project team.

## **Short-term Data Storage**

### **3. How will the data be stored in the short term?**

There are many ways to store data in the short term. First, you can choose to store data in physical or logical storage media, such as traditional relational databases: Oracle, MySQL; emerging NoSQL: HBase, Cassandra, Redis and so on. For data that has been centrally pre-processed, it can be stored using memory and the corresponding database can be created to facilitate subsequent management and invocation.

In addition, data storage is persistent, which allows data to be kept in a storage medium without being lost due to program exit or computer shutdown. Also, the data storage can be expanded as needed to store large amounts of data and can be expanded as the amount of data increases. In order to ensure the security of data, it can be protected by data encryption, access control, backup and other measures. At the same time, data efficiency is also an important feature of data storage, and data indexing, caching, compression, and other technologies can be used to improve data reading and writing speed and storage efficiency.

#### **3a What backup will you have in the in-project period to ensure no data is lost?**

During the project period, to ensure that we do not lose any data, we will take the following backup measures:

1. Regular Backups: We regularly back up critical data from the project, including documents, codebase, databases, and so on. This ensures that even if something unexpected happens, we are able to recover the data quickly.
2. Multi-location backups: In order to improve the reliability and security of data, we will perform multi-location backups. This way, even if there is a failure or disaster in one location, we can still recover data from other locations.
3. Cloud Backup: we will use a reliable cloud service provider to store the backup data. Cloud backup has high availability and flexibility to ensure data security and accessibility.
4. version control: For code and other editable files, we will use a version control system to track and manage changes across versions. This ensures that we can go back to a previous version for recovery if needed.
5. Test Recovery: After backing up data, we will periodically perform a test recovery operation to ensure the integrity and availability of the backup. This helps us to identify and resolve potential problems in a timely manner.

Please note that the above backup measures are routine practices to protect the security and reliability of project data. We will adjust and implement them accordingly according to the specific situation and needs of the project. If you have other questions about data backup, please feel free to ask.

## **Long-term Data Storage**

### **4. How the data will be stored in the long term?**

There are many different ways to store data for long periods of time, and the following are some common methods:

1. **Hard Disk Drive (HDD):** A hard disk drive is a common data storage device used to store data on rotating disks. Hard disk drives are typically used to store large amounts of data such as operating systems, applications, and personal files. The advantages of hard disk drives are that they cost less and have a larger storage capacity; the disadvantages are that they are relatively slow and susceptible to mechanical failures.
2. **Solid State Drives (SSDs):** SSDs use flash memory technology to store data and are faster and more durable than hard disk drives. However, SSDs are relatively expensive and have a small storage capacity.
3. **Tape:** Tape is an affordable method of data storage that uses magnetic material to store data. Tape is commonly used for backing up and archiving large amounts of data. The advantages of tape are low cost and large storage capacity; the disadvantages are slower access speeds and the need for specialized equipment to read and write data.
4. **Cloud storage:** Cloud storage is a service that stores data on a remote server over the Internet. The advantage of cloud storage is that data can be accessed anytime, anywhere without worrying about hardware failure; the disadvantage is that it relies on an Internet connection and there may be data security and privacy issues.
5. **CD-ROM:** CD-ROM is an optical data storage medium that can store data such as audio, video and software. The advantages of CD-ROMs are that they are inexpensive and easy to distribute; the disadvantages are that they have limited capacity and are easily damaged.

### **4a. Where have you decided to store it, why is this appropriate?**

The following factors need to be considered when choosing the method and location of long-term data storage:

1. **Volume of data:** Select the appropriate storage device or service based on the amount of data to be stored.
2. **Frequency of access:** If the data needs to be accessed frequently, choose a faster storage device or service.
3. **Cost:** Choose the right storage device or service according to your budget.
4. **Security:** For sensitive data, you need to consider data security and privacy issues and choose a reliable storage device or service.
5. **Scalability:** If the amount of data is expected to grow in the future, you need to choose a storage device or service with scalability.

### **4b. How long will it be stored for and why?**

The duration of storage of project data depends on a number of factors, such as the type of data, the

value of the data, the security of the data and the integrity of the data. Generally speaking, both backup and archiving belong to the data preservation stage, archiving in preserving data for a long time, and backup in preserving dynamic data for disaster recovery. For some data with important value, such as those in the medical and financial fields, long-term preservation may be required. However, long-term storage is not only costly but also difficult to manage due to changes in data formats and loss of physical storage media. For example, digital film and television have even shorter migration cycles, with Warner Bros. aggressively migrating data every three years because hard drives can wear out in three to five years. In the area of personal information protection, there is some tension between the requirement that data be kept for a minimum period of time (i.e., deleted as soon as possible) and the legal requirement that relevant data (containing personal information) be retained for at least a certain period of time for regulatory and other purposes. For example, for a project with a large volume of data, tens of millions of pieces of data are entered into the database every day and it is fixed that no data will be retained in the database for 23 hours.

**4c. Costs of storage - why are these appropriate? Costs related to long term storage will be permitted providing these are fully justified and relate to the project Full justification must be provided in Justification of Resources (JoR)**

Storage costs are the total costs incurred in maintaining inventory, and these costs include the cost of keeping the physical items and the cost of the capital tied up in the inventory itself. Specifically, storage costs are divided into two parts: fixed costs and variable costs:

1. Fixed storage costs: independent of the amount of inventory stored, and independent of the amount of inventory and the length of storage time. For example, warehouse depreciation, warehouse custodian fixed monthly wages.

2. Variable warehousing costs: the number of inventories in proportion to the number of inventories, the more the number of inventories, the higher the variable costs. For example, the interest cost of funds occupied by inventory, inventory insurance premiums, inventory salvage deterioration losses.

When considering the costs associated with long-term storage, it is important to ensure that these costs are fully justified and directly related to the project. This means that these costs need to be fully justified in the Justification of Resources (JoR) and demonstrate that they are indeed necessary for the project and compare favorably with other potential options. In addition, capital costs need to be considered, as storage costs include not only the cost of physical storage, but also the cost of the capital used.

## **Data Sharing**

### **5. How the data will be shared and the value it will have to others**

Project data can be shared in a number of ways, including:

1. Public release: Uploading data to a public database or website for anyone to access and use.

2. Data exchange: Exchanging data with other organizations or individuals to access the data they have.

3. Data licensing: Licensing data to other organizations or individuals, usually for a fee.

4. Data Sharing Agreement: Entering into a data sharing agreement with another organization or individual that specifies the responsibilities and obligations of both parties in relation to the use and sharing of data.

The value of these data to others is mainly in the following areas:

1. Scientific research: Researchers can utilize the data for various scientific studies, such as climate change, ecosystem restoration and urban planning.
2. Policy making: Government departments can make more scientific and effective policies and plans based on these data.
3. Business decision-making: Enterprises can utilize these data for market analysis, competitive analysis, risk assessment, etc., so as to make smarter business decisions.
4. Education and training: Educational institutions can utilize these data to provide students with practical teaching resources and improve teaching quality.
5. Public Participation: The public can access these data to understand the progress and results of the project and improve public participation and satisfaction.

#### **5a. How the data will enhance the area and how it could be used in the future?**

The main ways in which these data will enhance the value of the region are as follows:

1. Promoting sustainable development: through the analysis and utilization of project data, the sustainability of projects can be better assessed and monitored, thus ensuring a balanced development of projects in economic, social and environmental terms.
2. Improving resource utilization efficiency: Project data can help identify and optimize resource allocation, improve resource utilization efficiency and reduce waste.
3. Promote innovation and technological development: Project data can provide valuable information and insights for technological innovation and development, and promote regional technological progress and industrial upgrading.
4. Improve government governance: Project data can provide governments with real-time information on project progress, effects and problems, helping them to better manage projects and make decisions.
5. Enhance public trust and support: Through open and transparent data sharing, public trust and support for the project can be increased, creating a favorable social environment for the smooth implementation of the project.

#### **5b. Releasing the data - advise when you will be releasing and justify if not releasing in line with AHRC guidelines of a minimum of three years. If the data will have value to different audiences, how these groups will be informed?**

1. Data sensitivity: If the data relate to the privacy of individuals or sensitive information, additional protective measures may be required, which may result in a different timetable for releasing the data than the standardized guidelines. In such cases, a detailed explanation should be provided as to why a different timetable is required and what measures have been taken to protect the security and privacy of the data.
2. Emergencies: In certain emergency situations, such as public health crises, natural disasters or other events requiring an immediate response, there may be a need to release data quickly to support decision-making and action. In such cases, the nature of the emergency and why the data release needs to be prioritized should be described.
3. Legal or regulatory requirements: There may be specific legal or regulatory requirements that may require the release of data within a specific time frame. In this case, details of the relevant legal or regulatory requirements should be provided and an explanation given as to why these requirements result in a change in the release schedule.
4. Data timeliness: If the data is highly time-sensitive, such as financial market data or weather

forecasts, it may be necessary to release the data in real time or near real time to meet the needs of the audience. In this case, the timeliness of the data and why a faster release schedule is needed should be explained.

To ensure that information is accessible to different audiences, the following steps can be taken:

- Publicize data releases through official websites, press releases, social media, and other communication channels.
- Work with partners, stakeholders and key influencers to ensure they are aware of when and how the data will be released.
- If possible, make data available in multiple formats (e.g., spreadsheets, databases, visual charts, etc.) so that different audiences can access and use the data according to their needs.
- For sensitive or restricted data, consider setting up access controls or a request process to ensure that only the right people have access to the data.
- If there are multiple datasets or reports being published at the same time, a unified platform or page can be created to make it easy for audiences to find and access all relevant information.

### **5c. Will the data need to be updated? Include future plans for updating if this is the case.**

Whether project data need to be updated depends on the nature and objectives of the project. Updates are necessary if the project involves real-time data or data that need to reflect the latest situation. Future update plans should include the frequency and methodology for updating data on a regular basis to ensure timeliness and accuracy.

### **5d. Will the data be open or will you charge for it? Justify if charging to access the data**

Data can be either open or fee-based. Open data means that anyone is free to access and use the data, whereas data for which a fee is charged requires payment of a fee to access it. If a fee is charged for accessing data, it needs to be justified. This can be done in the following ways:

1. the cost of data collection and maintenance: if the cost of data collection and maintenance is high, e.g. complex data collection, cleansing and organizing work is required, then it is reasonable to charge a fee.
2. data quality and exclusivity: if the data is of high quality and exclusivity, i.e., the data is from a reliable and verified source and only a specific organization or individual owns the data, then charging a fee ensures the exclusivity and value of the data.
3. Data protection and privacy: If the data contains sensitive information or involves personal privacy, then charging a fee can provide better data protection measures to ensure data security and privacy.

### **5e. Financial requirements of sharing - include full justification in the JoR**

Shared financial requirements need to be fully justified in JoR. This may include the following:

1. Financial support: Sharing data may require additional funds to support the collection, organization, storage and maintenance of the data, etc. These funds may be used to purchase equipment, hire professionals, conduct data analysis, etc.
2. Fostering collaboration and innovation: Sharing data can foster collaboration and innovation. By making data available to other organizations or individuals, new ideas can be stimulated, new solutions can be discovered, and projects can be driven forward.
3. Public interest: Sharing data may have a positive impact on the public interest, e.g. improving social

services, enhancing efficiency in decision-making, and promoting scientific research. In this case, the financial requirements of shared data can be seen as a contribution to society.

In conclusion, the need for project data to be updated and the openness and chargeability of the data need to be determined on a case-by-case basis. Financial requirements for shared data need to be supported by a strong rationale, taking into account factors such as financial support, collaborative innovation and public interest.

## **Ethical and Legal Considerations**

### **6a. Any legal and ethical considerations of collecting the data**

There are certain ethical and legal requirements that do need to be followed when conducting data collection to ensure the legitimacy and sustainability of data analysis. Here are some key legal and ethical considerations:

1. **\*\*Laws and regulations\*\***: Countries and regions have different laws and regulations with strict rules on data collection, use, sharing and protection. For example, China has clearly stipulated the laws and regulations that should be complied with when carrying out data processing activities, such as respecting social morality and ethics, complying with business and professional ethics, being honest and trustworthy, fulfilling the obligation of data security protection, and assuming social responsibility. In addition, in order to cope with the arrival of the big data era, China is also actively promoting the legal infrastructure and supporting construction at the level of personal data rights.
2. **\*\*Rights and interests of data stakeholders\*\***: "My data, my master" is an ideal state. This means that from the collection, storage and transmission of data to its use and destruction, data stakeholders should be involved and protected by laws and regulations. In particular, when collecting and using personal data, although it is necessary for the public interest, it is also necessary to adhere to the lawful and reasonable application to ensure the security of personal data and privacy rights.
3. **\*\*Industry self-regulation and international cooperation\*\***: Relevant industry organizations should, in accordance with their statutes, formulate data security codes of conduct and group standards in accordance with the law, strengthen industry self-regulation, and guide their members to strengthen data security protection. At the same time, the State also actively carries out international exchanges and cooperation in the fields of data security governance, data exploitation and utilization, and participates in the formulation of international rules and standards related to data security.

To summarize, data collection is not only a technical issue, but also a complex issue involving many aspects of law, ethics and society. When data collection is carried out, these factors must be considered comprehensively to ensure the legality, security and morality of the data.

### **6b. Legal and ethical considerations around releasing and storing the data - anonymity of any participants, following promises made to participants**

The legal and ethical issues involved in publishing and storing data are quite extensive. Considered from a legal perspective, the Data Security Law of the People's Republic of China stipulates the legal requirements to be observed in carrying out data processing activities. This includes respecting social morality and ethics, complying with business ethics and professional ethics, being honest and trustworthy, fulfilling data security protection obligations, and assuming social responsibility. In addition, where laws and administrative regulations stipulate the purpose and scope of data collection and use, data shall be collected and used within the purpose and scope stipulated in the laws and administrative regulations.

In terms of ethics, respect for personal privacy is the most basic requirement. Private information of others should not be collected, used or disclosed without authorization or legitimate reasons. This not only helps to safeguard an individual's right to privacy, but also helps to build public trust in technology and data.

In addition to the above legal provisions and ethical principles, there are also industry organizations that, in accordance with their charters, formulate data security codes of conduct and group standards in accordance with the law, strengthen industry self-regulation, and guide their members to strengthen data security protection. At the same time, the State has actively engaged in international exchanges and cooperation in the areas of data security governance and data exploitation and utilization, and has participated in the formulation of international rules and standards related to data security.